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Ovarian Cancer

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CONTRACTING ORGANIZATION: Beth Israel Medical Center  
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## INTRODUCTION

The overall goal of this study is to determine the levels of distress in women with a family history of ovarian cancer and to identify the mediating factors between risk of developing ovarian cancer and distress. The proposed study will use 180 first-degree relatives (FDR) of women diagnosed with ovarian cancer in a cross-sectional design. Information the ovarian cancer index case provides will be used to identify maternal relatives (mothers, sisters, or daughters). Women will be queried about their objective and subjective risk status, their knowledge of ovarian cancer and risk factors, their uncertainty about ovarian cancer, levels of anxiety and depression, their personality traits of mastery, tolerance for ambiguity, and optimism, and their interest in genetic testing. With the results generated by this study, specific interventions can be designed and tested to improve adjustment of women at high risk for ovarian cancer.

## BODY

### Work Accomplished as Related to Statement of Work (see Appendix A)

**Task 1** - All the items in Task 1 were accomplished. Unfortunately the research assistant resigned in the beginning of December 2001 and we are awaiting a replacement. During that time Dr. Kash has been working on the study and is currently awaiting IRB approval (expected by April 5, 2002) to begin recruitment of women into the study.

**Task 2** - We have not yet begun accrual and are waiting for IRB approval. We are requesting a change in Task 2. Since this study is behind the time schedule we want to include women from the Continuum Health Partners cancer registry and Cancer Center support programs listing. In this stepped-up recruitment, we will be able to recruit 180 by the end of the study period (October 2003).

We are obtaining the family history of cancer from the first-degree relative, not the index case. We already know the index cases have ovarian cancer and we do not want to burden them by asking more questions. Also we want to find out what the first-degree relative knows about their cancer history. The first-degree relative will provide a brief family history of all cancers in the family on the questionnaire. The purpose of the family cancer history is to see if there are other cancers that may potentially be genetically predisposing to cancer.

**Task 3** - We have not yet begun Task 3.

### Problems In Accomplishing Tasks as related to Statement of Work

The Gynecological-Oncology team at Beth Israel Medical Center left in April 2000 and was not replaced until June 2001. One of the key members of the Gynecological-Oncology team at St. Luke's-Roosevelt Hospital Center resigned and was not replaced until July 2001. Because there was only one gynecological oncologist within Continuum Health Partners Partners (Beth Israel Medical Center and St. Luke's-Roosevelt Hospital Center) for over one year, this protocol has been extremely delayed. Therefore we changed our original plan from only approaching women in the clinic to using the Continuum Health Partners cancer registry and Cancer Center support programs listing (provided by Cindy Turkeltaub, MSW, support program coordinator). There are approximately 120 women with ovarian cancer who have participated in our support programs. We have also enlisted the SHARE program in Manhattan to recruit women with ovarian cancer to contact their sisters and daughters for participation. The SHARE program is a self-help group for women with breast and ovarian cancer. The coordinator of the ovarian groups, Nyrvah Richards, has agreed to recruit participants. She believes this is a timely topic for family members of women with ovarian cancer. Many of the women who attend SHARE have participated in one of our support programs at Beth Israel.

In addition, the research assistant resigned on December 5, 2001 and has not been replaced. The Human Resources office has not been able to locate anyone who meets the requirements for the position. Dr. Kash, the Principal Investigator, has been working extra time to bring about the stepped-up recruitment process in order to obtain the sample size (180 women) stated in the Statement of Work in Task 2. We have identified a potential research assistant who will be graduating college with a BA in Psychology in May. She will begin to volunteer with us until we can transition her into a full time position.

In summary, Task 1 has been completed and we expect to begin Tasks 2 and 3 within the next two weeks. None of the goals or objectives of the study have changed. The conceptual model for this study (*see Appendix B*) is the same as in the original proposal. However, we are planning on using a stepped-up recruitment process in order to reach our sample size of 180 women by the end of the study period (October 2003).

### KEY RESEARCH ACCOMPLISHMENTS

There have been none to-date.

## REPORTABLE OUTCOMES

An abstract (*see Appendix C*) was presented at the 7<sup>th</sup> International Meeting on Psychosocial Aspects of Genetic Testing for Hereditary Breast and/or Ovarian Cancer (HBOC) and Hereditary Non-Polyposis Colorectal Cancer (HNPCC) in Frankfurt, Germany on the 27<sup>th</sup> and 28<sup>th</sup> September 2001. This abstract revolved around the conceptual model of this study (*see Appendix B*) and was well-received by international colleagues who expressed interest in the model of uncertainty in defining levels of distress in women with a family history of ovarian cancer.

## CONCLUSIONS

We are anticipating approval of our protocol by the IRB by April 5, 2002. Attached are the Informed Consent (*see Appendix D*) and the study questionnaire (*see Appendix E*). They have already been sent the DoD Regulatory Affairs Office. Once we receive the institutional IRB approval, we will forward it to Mercy Swatson. Within the next couple of months we anticipate recruiting a sufficient number of women into this study to put us on track with recruitment. There are 120 women who have attended support programs and 190 women listed in the cancer registry. If only one-half of these women provide names of their first-degree relatives and one-half of the first-degree relatives are willing to participate, we will be able to accrue 77 women within approximately two months. This would be in addition to approaching women with ovarian cancer in the clinic at the time of their visit. Initially we had anticipated recruiting 64 women per year. By using the cancer registry and support program listing, we will be able to attain our goal of recruiting 180 women by October 2003.

## **APPENDIX A**

## STATEMENT OF WORK

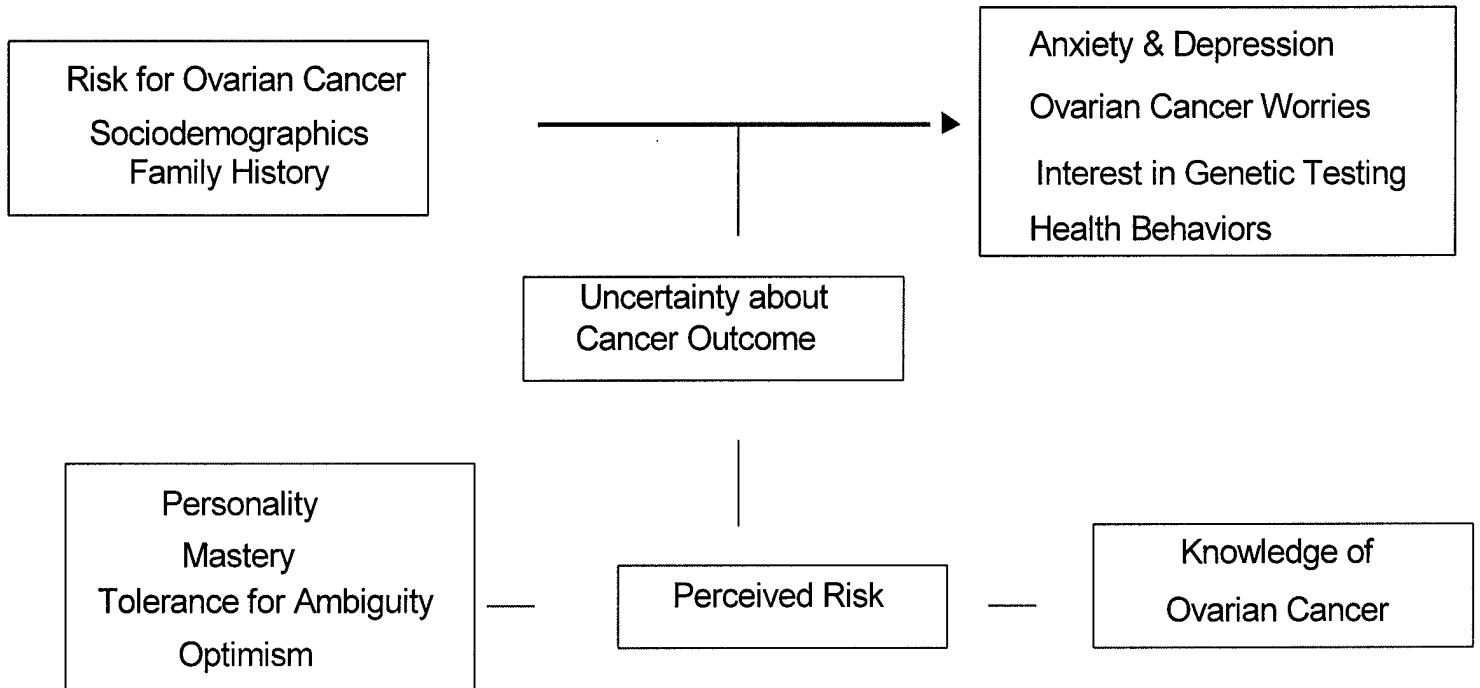
### LEVELS OF DISTRESS IN WOMEN AT RISK FOR OVARIAN CANCER

- Task 1.** - Preparation of materials, data program, and training of staff Month 1
- a. Measures are finalized.
  - b. Questionnaires copies.
  - c. Scripts for contacting potential participants are finalized.
  - d. Research assistant hired and trained in recruitment procedures.
  - e. Codebook will be finalized.
  - f. Program for data entry will be written.
- Task 2.** - Recruitment of participants - Month 2-34
- a. Index cases with diagnosed ovarian cancer will be consecutively approached during scheduled outpatient visits. **Index cases recruited from the cancer registry and the cancer support programs will be sent a letter describing the study.**
  - b. Permission obtained to contact unaffected female first-degree relatives (FDR) (total N=180) of index cases.
  - c. Family history will be obtained from the first-degree relative
  - d. Research assistant contacts potential participants using telephone script.
  - e. Study packet mailed to those interested in participation.
  - f. Participants contacted by telephone for interview completion.
- Task 3.** - Data entry and analyses - Month 4-36
- a. Data entry is begun in month 4.
  - b. Preliminary data analyses are begun in month 18.
  - c. Final analyses are completed in month 36.



## **APPENDIX B**

## CONCEPTUAL FRAMEWORK



## **APPENDIX C**

## Levels of Distress in Women with a Family History of Ovarian Cancer

Kathryn M. Kash, Ph.D. & Mary Kay Dabney, M.S.

Beth Israel Medical Center, New York, NY, USA

*Introduction.* There is evidence to suggest that women with a family history of ovarian cancer are at higher than average risk for the disease and a small percentage are gene mutation carriers. To date, there have been no systematic studies of women who are at this increased risk because of their family history and the relationship between actual risk and levels of emotional distress as mediated by personality factors, perception of risk, and knowledge of ovarian cancer risk factors. Our proposal will envelope a much broader scope than previous work by looking at the distress associated with increased risk for ovarian cancer in FDR's (first-degree relatives) of index cases, rather than women attending screening clinics, while examining the predictor variables of such distress. We are particularly interested in how specific personality traits mediate level of distress. For example, one would expect that women who have a sense of mastery and optimism and better tolerance for ambiguity, would be able to handle the uncertainty regarding being at increased risk for ovarian cancer and thus feel less distressed. In addition, we plan to look at the FDR's knowledge of genetic testing for ovarian cancer, perception of being a gene mutation carrier, and interest in genetic testing (as it relates to ovarian cancer). Perhaps the most serious limitation of genetic testing is that state-of-the-art diagnostics do not match test information. To receive positive genetic test results when there is no adequate screening is tragic.

*Goals of Study.* The overall goal of this study is to determine the levels of distress in women with a family history of ovarian cancer and to identify the mediating factors between risk of developing ovarian cancer and distress. With the results generated by this study, specific interventions can be designed and tested to improve adjustment of women at high risk for ovarian cancer.

*Research Design.* The proposed study will use 180 first-degree relatives (FDR) of women diagnosed with ovarian cancer in a cross-sectional design. Information the ovarian cancer index case provides will be used to identify maternal relatives (mothers, sisters, or daughters). Women will be queried about their objective and subjective risk status, their knowledge of ovarian cancer and risk factors, their uncertainty about ovarian cancer, levels of anxiety and depression, their personality traits of mastery, tolerance for ambiguity, and optimism, and their interest in genetic testing.

## **APPENDIX D**

**Beth Israel Medical Center**



**St. Luke's Roosevelt Hospital Center**



**CONSENT FOR PARTICIPATION IN RESEARCH**

\_\_\_\_\_  
Name of Subject (*Printed*)

\_\_\_\_\_  
Kathryn M. Kash, Ph.D.  
Principal Investigator

\_\_\_\_\_  
Title of Project

Page 1 of \_\_\_\_\_ Pages

IRB/COSA # \_\_\_\_\_

Attached to this form is a full description of the study in which we are asking you to participate. The description tells you about the **reason for the study**, the **procedures, interviews**, and **drugs or devices** which may be involved; **the duration of the study**; and any **risks and benefits to you**. The description also gives you information about **other medical treatments** you may receive if you do not want to participate in this study.

If you have questions concerning this research project or your rights as a research subject, or if you have a research-related injury, you may telephone the Principal Investigator

\_\_\_\_\_  
Kathryn M. Kash, Ph.D. at \_\_\_\_\_ (212) 844-8794 or  
the Patient Representative \_\_\_\_\_ Laura Weil at \_\_\_\_\_ (212) 420-3818

**CONSENT TO PARTICIPATE -- ADULT**

I have read the attached study description. The purpose of the study, the risks of the study and what it means to participate in the study have all been explained to me, and my questions have been answered. I agree to participate in the study and agree to take all the tests or procedures mentioned in the study description. If I am injured in the study, I understand only immediate essential medical treatment will be provided free of charge. The hospital will not pay me for any injury. I understand that participating in the study is voluntary, that I can decline to participate, and that I can stop participating at any time. I also understand that my decision to participate in or to withdraw from the study will not affect the health care I receive, now or in the future. I have been told that records of this investigation will be kept confidential to the extent permitted by law but are subject to inspection by the U. S. Food and Drug Administration and study sponsors.

\_\_\_\_\_  
Signature of Subject  
or Legal Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Authorized  
Representative or Person  
Giving Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Relationship to Subject

I, \_\_\_\_\_, have clearly and fully explained to the above  
subject (or person giving consent) the nature, requirements and risks of the study.

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

May be Used to  
Enroll Subjects Until

(stamp)

DISTRIBUTION: Original to Research Records; copies for Subject (or Person Giving Permission), Investigator, Hospital Chart and Pharmacy (when appropriate).

## **PARTICIPANT INFORMED CONSENT FOR RESEARCH**

You are being asked to participate in a clinical research study. The doctors at the Beth Israel Medical Center and St. Luke's-Roosevelt Hospital Center study the nature of disease and attempt to develop improved methods of diagnosis and treatment. This is called clinical research. In order to decide whether or not you should agree to be part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent.

This consent form gives detailed information about the research study, which the investigators will discuss further with you. Once you understand the study, you will be asked to sign this form if you wish to participate. You will have a copy to keep as a record.

The research study being proposed to you is:

### **LEVELS OF DISTRESS IN WOMEN WITH A FAMILY HISTORY OF OVARIAN CANCER**

#### **PURPOSE OF THE RESEARCH**

The purpose of this study is to learn about women who have a first-degree relative (mother or sister) with ovarian cancer. You have been selected to participate in this research project because you have a mother or a sister with ovarian cancer. We want to find out what you know about ovarian cancer, what you think your risk for developing ovarian cancer is, your emotional distress levels, and your attitudes toward genetic testing.

#### **DESCRIPTION OF THE RESEARCH**

If you agree to participate in the study, you will be asked to sign this consent form return it using the stamped envelope that was provided to you. Once we receive this consent form we will send you a survey to complete. This survey will take you approximately 30 minutes to complete. We will contact you, by telephone, approximately one week after these materials are mailed to you in order to make sure you have received them and to write down your responses to the questions. We will ask you to mail us back the completed survey for our records.

#### **RISK AND BENEFITS**

We do not see any risk to you in participating in the study other than the possibility that you may find the reporting or discussing of some of your emotions uncomfortable. However, a trained interviewer will be available by phone to discuss this with you, should it occur. While the study may not benefit you directly, your participation in this study will provide useful information in the future for women with a family history of ovarian cancer.

#### **FINANCIAL COST OF PARTICIPATION**

The study interviews will be carried out at no charge to you. In fact, you will receive \$20 in appreciation for your time and effort in participating in the study. A check for this amount will be mailed to you once your informed consent is received and your questionnaire is completed and returned.

### CONFIDENTIALITY AND PRIVACY

Your research and center records are confidential. All records related to your involvement in this study will be coded to insure privacy and are not part of your medical records. Dr. Kash will keep the names and code numbers in a locked file cabinet. Your name or any other personally identifying information will not be used in reports or publications resulting from the study. The Food and Drug Administration (FDA) and representatives from the U.S. Army Medical Research, Development, Acquisition and Logistics Command may inspect the records of this research. As a result, they may see your name: but they are bound by the rules of confidentiality not to reveal your identity to others.

### RIGHT TO REFUSE OR WITHDRAW

The choice to enter, or not to enter, this study is yours. If you decide not to participate, you may do so without prejudice. If you enter the study, you still have the right to withdraw at any time.

### SIGNATURE OF RESEARCH PARTICIPANT

I have read the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Address

Initials of Participant: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Initials of Interviewer: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_



## **APPENDIX E**

**BACKGROUND INFORMATION**

Please fill in or check off (✓) the answer to the questions below. We appreciate your participation in this project; we could not complete it without you. Thank you for your time.

1. What is your current age? \_\_\_\_\_ Date of Birth? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Month Day Year
2. What is your marital status? Please check (✓) one box.
  - ☐ Single or never married
  - ☐ Married, or living with someone as married
  - ☐ Separated or divorced
  - ☐ Widowed
  - ☐ Other (*please specify*) \_\_\_\_\_
3. Which of the following do you consider yourself to be? Please check (✓) one box.
  - ☐ African American or Black
  - ☐ Asian or Pacific Islander
  - ☐ Caucasian or White
  - ☐ Hispanic
  - ☐ Native American or Native Canadian
  - ☐ Other (*please specify*) \_\_\_\_\_
4. Please check (✓) the highest grade you have completed in school.
  - ☐ Less than high school
  - ☐ High school or GED
  - ☐ Some college or technical school
  - ☐ College graduate
  - ☐ Post-graduate or professional school
5. Please check (✓) the box, which indicates your current employment status.
  - ☐ Full-time
  - ☐ Part-time
  - ☐ Not employed (including student or homemaker)
  - ☐ Retired
6. What is your religious background? Please check (✓) one box.
  - ☐ Baptist
  - ☐ Catholic
  - ☐ Jewish
  - ☐ Protestant
  - ☐ Other (*please specify*) \_\_\_\_\_
  - ☐ None

7. What is your annual family income? Please check (✓) one box.

☐ Less than \$20,000

☐ \$50,001 – \$75,000

☐ \$20,000 – \$35,000

☐ Greater than \$75,000

☐ \$35,001 – \$50,000

☐ Don't want to answer

8. The following questions are about your religious or spiritual beliefs. While they may seem personal, your answers are important in understanding how you make decisions regarding health care. If you prefer to skip these questions, please go to the next page. Please circle (○) one answer for each question.

1 – Extremely

3 – Somewhat

5 – Not at all

2 – Quite a bit

4 – A little

8 – Not applicable (no religious affiliation)

- a. To what extent was religion practiced/observed in your home as you were growing up? ..... 1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 8
- b. At the present time, how strict are you in the observance/practice of your religion? ..... 1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 8
- c. Do you currently practice/observe a religion? ..... 1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 8
- d. Do you consider yourself a religious person? ..... 1 ----- 2 ----- 3 ----- 4 ----- 5
- e. How strongly do spiritual beliefs affect your values and decision making? ..... 1 ----- 2 ----- 3 ----- 4 ----- 5

9. Please fill in the information requested for any family members with cancer. For example, if a relative had breast cancer please write breast cancer under type of cancer. If information is unknown, please write "UNK."

EXAMPLE

Family Member	Type Of Cancer	Age at Diagnosis	Alive or Deceased	If Deceased, Age at Death
Your Mother	<i>Breast</i>	<i>42</i>	<i>Deceased</i>	<i>53</i>

Family Member	Type Of Cancer	Age at Diagnosis	Alive or Deceased	If Deceased, Age at Death
Your Mother				
Your Father				
Mother's Mother				
Mother's Father				
Father's Mother				
Father's Father				
Mother's Sister				
Mother's Brother				
Father's Sister				
Father's Brother				
Your Sister				
Your Brother				
Other: _____				

## OVARIAN CANCER AND SCREENING

Below is a list of comments made by women about breast or ovarian cancer and screening. Please indicate by circling next to each item how frequently these comments were true for you DURING THE LAST ***THIRTY*** DAYS ABOUT ***OVARIAN CANCER***. If it did not occur during that time please circle 0 in the "Not at all" column.

	Not at all	Rarely	Sometimes	Often
1. I tried not to think about ovarian cancer.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Any reference to ovarian cancer brought up strong feelings in me. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Whenever I heard about a friend or public figure with ovarian cancer, I got more anxious about developing ovarian cancer.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. When I thought about having a gynecological examination, I got more anxious about ovarian cancer.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I thought that the older I get, the more I think about the possibility of getting ovarian cancer.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Other things kept making me think about ovarian cancer.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I was fearful of what might be found during a pelvic examination by my doctor. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Just hearing the words "ovarian cancer" scared me .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CANCER WORRIES

Please circle (○) one answer for each question.

	Not at all or Rarely	Sometimes	Often	A Lot
1. During the past month, how often have you thought about your own chances of developing ovarian cancer? .....	1	2	3	4
2. During the past month, how often have thoughts about your chances of getting ovarian cancer affected your mood? .....	1	2	3	4
3. During the past month, how often have thoughts about your chances of getting ovarian cancer affected your ability to perform your daily activities? .....	1	2	3	4

## OVARIAN AND BREAST CANCER RISK

1. What are your chances of developing *ovarian* cancer on a scale of

☐ 0%   
 ☐ 10%   
 ☐ 20%   
 ☐ 30%   
 ☐ 40%   
 ☐ 50%   
 ☐ 60%   
 ☐ 70%   
 ☐ 80%   
 ☐ 90%   
 ☐ 100%

2. What are the average woman's chances of developing *ovarian* cancer on a scale of

☐ 0%   
 ☐ 10%   
 ☐ 20%   
 ☐ 30%   
 ☐ 40%   
 ☐ 50%   
 ☐ 60%   
 ☐ 70%   
 ☐ 80%   
 ☐ 90%   
 ☐ 100%

3. A woman is more likely to develop **ovarian** cancer if she: (Check [☐] all that you think are correct)

- |  |  |
|--|--|
| <input type="checkbox"/> has no children   | <input type="checkbox"/> has had children  |
| <input type="checkbox"/> has her first child after the age of 30                           | <input type="checkbox"/> is past menopause (change of life)                                |
| <input type="checkbox"/> uses an anti-perspirant as a deoderant                            | <input type="checkbox"/> had a Sexually Transmitted Disease                                |
| <input type="checkbox"/> takes birth control pills   | <input type="checkbox"/> has had breast cancer   |
| <input type="checkbox"/> had previous abortion or miscarriage                              | <input type="checkbox"/> uses talcum powder  |
| <input type="checkbox"/> had sex as a teenager   | <input type="checkbox"/> had sex as a teenager   |
| <input type="checkbox"/> has relatives on her mother's side<br>who have had ovarian cancer | <input type="checkbox"/> has relatives on her father's side<br>who have had ovarian cancer |
| <input type="checkbox"/> used drugs (hormones) to get pregnant                             | <input type="checkbox"/> has had ovarian cysts   |
| <input type="checkbox"/> has been on hormone replacement therapy                           | <input type="checkbox"/> have no idea  |

4. What are your chances of developing *breast* cancer on a scale of

☐ 0%   
 ☐ 10%   
 ☐ 20%   
 ☐ 30%   
 ☐ 40%   
 ☐ 50%   
 ☐ 60%   
 ☐ 70%   
 ☐ 80%   
 ☐ 90%   
 ☐ 100%

5. What are the average woman's chances of developing *breast* cancer on a scale of

☐ 0%   
 ☐ 10%   
 ☐ 20%   
 ☐ 30%   
 ☐ 40%   
 ☐ 50%   
 ☐ 60%   
 ☐ 70%   
 ☐ 80%   
 ☐ 90%   
 ☐ 100%

## GENETIC TESTING INFORMATION

The following questions relate to what you may or may not know about the breast/ovarian cancer (BRCA1 or BRCA2) genes. Please check (✓) the box that corresponds to whether you think the item is **TRUE** or **FALSE**. If you are **NOT SURE** of a particular answer, please check (✓) the last box to the right.

**TRUE      FALSE      NOT SURE**

1. About one in ten women have a BRCA1 or BRCA2 gene mutation..... ☐ ----- ☐ ----- ☐
2. A woman who doesn't have an altered BRCA1 or BRCA2 gene  
can still get ovarian or breast cancer..... ☐ ----- ☐ ----- ☐
3. A woman who has her ovaries removed can still get ovarian cancer ..... ☐ ----- ☐ ----- ☐
4. All women who have a BRCA1 or BRCA2 gene mutation  
will get ovarian or breast cancer. .... ☐ ----- ☐ ----- ☐
5. A father can pass down a BRCA1 or BRCA2 gene mutation to his daughter... ☐ ----- ☐ ----- ☐
6. A woman who has an altered BRCA1 or BRCA2 gene mutation  
has a higher risk of ovarian cancer. .... ☐ ----- ☐ ----- ☐
7. A woman who gets ovarian cancer at age 65 is more likely to have a BRCA1  
or BRCA2 gene mutation than a woman who gets ovarian cancer at age 35.... ☐ ----- ☐ ----- ☐
8. A woman who has a sister with an altered BRCA1 or BRCA2 gene has  
a 50% chance (1 in 2) of also having a BRCA1 or BRCA2 gene. .... ☐ ----- ☐ ----- ☐

## UNCERTAINTY ABOUT OVARIAN CANCER RISK

The following questions ask about how certain you are about your risk for ovarian cancer.  
Please circle [O] one number for each of the 12 questions.

- |  | Strongly Disagree | Disagree | Agree   | Strongly Agree |
|--|-------------------|----------|---------|----------------|
| 1. I don't know if something is wrong with me .....                                    | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 2. I have a lot of questions without answers. ....                                     | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 3. I am unsure if my risk will get better or worse. ....                               | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 4. It is unclear how high my risk is. ....   | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 5. I do not know when to expect things<br>will be done to me. . ....                   | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 6. I understand everything explained to me. . ....                                     | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 7. The doctors say things to me that could<br>have many meanings. . ....               | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 8. My risk is too complex to figure out. . ....  | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 9. Because of the unpredictability of my risk,<br>I cannot plan for the future. . .... | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 10. I have been given many different opinions<br>about my risk. . ....                 | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 11. It is not clear what is going to happen to me. . ....                              | 1 -----           | 2 -----  | 3 ----- | 4 -----        |
| 12. They give me so much information that<br>I cannot tell what is important. . ....   | 1 -----           | 2 -----  | 3 ----- | 4 -----        |

## DECISION-MAKING

We are interested in your attitudes about decision-making or problem solving in general, not specific to any one situation. What is the extent of your agreement with each of the following statements? (Please check [✓] one box for each item in the six-point scale.)

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1) It really disturbs me when I am unable to follow another person's train of thought.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) If I am uncertain about the responsibilities involved in a particular task, I get very anxious.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Before any important task, I must know how long it will take .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I don't like to work on a problem unless there is a chance of getting a clear-cut answer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) The best part of working on a jigsaw puzzle is putting in that last piece .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) I am often uncomfortable with people unless I feel that I can understand their behavior.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) A good task is one in which what is to be done and how it is to be done are always clear .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## HEALTH BEHAVIORS

Some people alter their lifestyle to maintain good health. Do you do any of the following to maintain your health? Please check (✓) all that apply?

- ☐ Exercise regularly (three to four times a week)
- ☐ Engage in stress reducing activities other than exercise (for example; yoga, meditation, relaxation)
- ☐ Maintain moderate consumption of alcohol      [If you do not drink alcohol, please ✓ here: ☐ ]
- ☐ Reduce tobacco use or quit using tobacco      [If you do not smoke, please ✓ here: ☐ ]
- ☐ Maintain moderate consumption of caffeine      [If you do not have any caffeine, please ✓ here: ☐ ]
- ☐ Wear a seat belt in a car
- ☐ Avoid known health hazards (for example; irradiation, chemical or strong sun exposure)
- ☐ Monitor cholesterol intake and blood pressure level
- ☐ Take vitamins
- ☐ Monitor diet
- ☐ Other health conscious things not listed above: \_\_\_\_\_

## SYMPTOMS

Listed below are some symptoms of strain that people sometimes have. Please read each one carefully and check (✓) the box that best reflects how much that symptom has bothered you during the past month.

	Not at all	Rarely	Sometimes	Often
1. Suddenly scared for no reason.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling fearful .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Faintness, dizziness, or weakness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Nervousness or shakiness inside .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Heart pounding or racing.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Trembling .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Feeling tense or keyed up.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Headaches.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Spells of terror panic .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Feeling restless, can't sit still .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Feeling low in energy, slowed down.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Blaming yourself for things.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Crying easily.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Loss of sexual interest or pleasure .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Poor appetite.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Difficulty falling asleep, staying asleep .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Feeling hopeless about the future.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Feeling blue .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Feeling lonely .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Feeling trapped or caught.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Worrying too much about things.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Feeling no interest in things .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Thoughts of ending your life .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Feeling everything is an effort.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Feelings of worthlessness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## FEELINGS

Listed below are a number of statements which people have used to describe themselves. Read each statement and then circle the number to the right of the statement to indicate how you **feel right now**, that is, *at this moment*. Do not spend too much time on any one statement but give the answer which best describes your present feelings.

1 Not At All	2 Somewhat	3 Moderately So	4 Very Much So
1. I feel calm .....	1 2 3 4	11. I feel anxious.....	1 2 3 4
2. I feel secure .....	1 2 3 4	12. I feel comfortable .....	1 2 3 4
3. I feel self-confident .....	1 2 3 4	13. I am jittery .....	1 2 3 4
4. I feel nervous.....	1 2 3 4	14. I feel "high strung" .....	1 2 3 4
5. I am tense .....	1 2 3 4	15. I am relaxed.....	1 2 3 4
6. I am regretful.....	1 2 3 4	16. I feel content .....	1 2 3 4
7. I feel at ease .....	1 2 3 4	17. I am worried .....	1 2 3 4
8. I feel upset.....	1 2 3 4	18. I feel over excited and "rattled" ....	1 2 3 4
9. I am presently worrying over possible misfortunes ....	1 2 3 4	19. I feel joyful.....	1 2 3 4
10. I feel rested .....	1 2 3 4	20. I feel pleasant .....	1 2 3 4

Below is a list of feelings, attitudes, and behaviors that you might have experienced. Please circle the number which best describes how often you have had these experiences during the **PAST WEEK**.

0 Rarely or None of the Time (Less than 1 Day)	1 Some or a Little of the Time (1 – 2 Days)	2 Occasionally or a Moderate Amount of Time (3 – 4 Days)	3 Most or All of the Time (5 – 7 Days)
1. I was bothered by things that usually don't bother me. ....	0	1	2
2. I did not feel like eating; my appetite was poor.....	0	1	2
3. I felt that I could not shake off the blues even with help from my family or friends. ....	0	1	2
4. I felt that I was just as good as other people. ....	0	1	2
5. I had trouble keeping my mind on what I was doing.....	0	1	2
6. I felt depressed (blue or "down"). .....	0	1	2
7. I felt that everything I did was an effort. ....	0	1	2
8. I felt hopeful about the future. ....	0	1	2
9. I thought my life had been a failure. ....	0	1	2
10. I felt fearful. ....	0	1	2
11. My sleep was restless.....	0	1	2
12. I was happy. ....	0	1	2
13. I talked less than usual. ....	0	1	2
14. I felt lonely.....	0	1	2
15. People were unfriendly. ....	0	1	2
16. I enjoyed life. ....	0	1	2
17. I had crying spells. ....	0	1	2
18. I felt sad.....	0	1	2
19. I felt that people dislike me.....	0	1	2
20. I could not get "going." .....	0	1	2

## SCREENING BEHAVIORS

This section asks about your experience and plans for having screening tests. Please check [✓] the box that comes closest to your situation.

1. Have you ever had a Pap smear, which is when the doctor or nurse practitioner exams your vagina and takes a Q-tip to get some fluid from your cervix and put it on a glass slide?

☐ Yes      ☐ No      ☐ Refused      ☐ Don't know/Not sure

*If yes, How long ago was this?*

☐ Within 1 year

☐ 1 – 3 years

☐ More than 3 years

Do you plan to have a Pap smear within the next year? ☐ Yes ☐ No

2. Have you ever had a mammogram, which is an X-ray of your breasts?

☐ Yes      ☐ No      ☐ Refused      ☐ Don't know/Not sure

*If yes, How long ago was this?*

☐ Within 1 year

☐ 1 – 3 years

☐ More than 3 years

Do you plan to have a mammogram within the next year? ☐ Yes ☐ No

3. Have you ever had a clinical breast exam, which is when a doctor or a nurse practitioner exams the breasts?

☐ Yes      ☐ No      ☐ Refused      ☐ Don't know/Not sure

*If yes, How long ago was this?*

☐ Within 1 year

☐ 1 – 3 years

☐ More than 3 years

Do you plan to have a clinical breast exam within the next year? ☐ Yes ☐ No

4. Have you ever had a CA-125, which is a blood test done to screen for ovarian cancer?

☐ Yes      ☐ No      ☐ Refused      ☐ Don't know/Not sure

*If yes, How long ago was this?*

☐ Within 1 year

☐ 1 – 3 years

☐ More than 3 years

Do you plan to have a CA-125 within the next year? ☐ Yes ☐ No

5. Have you ever had a transvaginal ultrasound, which is when a probe is inserted into the vagina to image the ovaries ?

☐ Yes      ☐ No      ☐ Refused      ☐ Don't know/Not sure

*If yes, How long ago was this?*

☐ Within 1 year

1 – 3 years

☐ More than 3 years

Do you plan to have a transvaginal ultrasound within the next year? ☐ Yes ☐ No

6. Do you currently perform breast self-examination (BSE)? ☐ Yes ☐ No

If **yes**, how often did you perform BSE in the past **six months**?

(indicate number of times)

## LIFE ORIENTATION

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no right or wrong answers. Answer according to your own feelings, rather than how you think "most people" would answer.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. In uncertain times, I usually expect the best.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. It's easy for me to relax.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. If something can go wrong for me, it will .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I always look on the bright side of things.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I'm always optimistic about my future.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I enjoy my friends a lot. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. It's important for me to keep busy. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I hardly ever expect things to go my way.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Things never work out the way I want them to. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I don't get upset too easily.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I'm a believer in the idea that "every cloud has a silver lining". ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I rarely count on good things happening to me. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## MASTERY SCALE

How strongly do you agree or disagree that:

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I have little control over the things that happen to me.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. There is really no way I can solve some of the problems I have .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. There is little I can do to change many of the important things in my life. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I often feel helpless in dealing with the problems of life.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Sometimes I feel that I'm being pushed around in life.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. What happens to me in the future mostly depends on me .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I can do just about anything I really set my mind to do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## GENETIC TESTING

You may have heard about genes called BRCA1 and BRCA2 and that a mutation in one of these genes causes ovarian and/or breast cancer predisposition in a small number (approximately 5%) of families with family histories of ovarian and/or breast cancer. It is believed that these genes may be passed from one generation to the next in these affected families. In these families, some family members will inherit the gene mutations and others will not. Both men and women have an equal chance of inheriting and passing on these altered genes.

Women, who carry the BRCA1 or BRCA2 gene mutations, with family histories of ovarian and breast cancers, have an increased risk for developing both ovarian and breast cancers. A woman who has a BRCA1 or BRCA2 mutation has a 20–60% lifetime risk of developing ovarian cancer. A woman who has a BRCA2 mutation has approximately a 20% lifetime risk of developing ovarian cancer. BRCA1 and BRCA2 gene mutation carriers have a 50% chance of passing these gene mutations onto each child.

It is possible at this time to test individuals, to see if they are carrying the gene (BRCA1 and BRCA2) mutations for ovarian and breast cancer.

1. Did you hear about the clinical testing for the breast cancer genes (BRCA1 and BRCA2)?

☐ Yes      ☐ No      ☐ Not Sure

If yes, where did you hear about it?

☐ Newspaper      ☐ Television      ☐ Magazine      ☐ Friend/Relative      ☐ Physician

☐ Other: \_\_\_\_\_

2. Have you ever had genetic testing for a BRCA1 or BRCA2 gene mutation?

☐ Yes      ☐ No      ☐ Not Sure

If yes, are you gene mutation carrier for: ☐ BRCA1 ☐ BRCA2      ☐ Negative      ☐ Inconclusive Results

*If you have already had genetic testing, please go to Question #6.*

*If you have NOT had genetic testing, please complete Question #3 through #5.*

3. How likely do you think it is that you have a BRCA1 or BRCA2 gene mutation?

Please check (✓) one for each mutation.

BRCA1 mutation

- ☐ — extremely likely  
☐ — very likely  
☐ — moderately likely  
☐ — somewhat likely  
☐ — not at all likely

BRCA2 mutation

- ☐ — extremely likely  
☐ — very likely  
☐ — moderately likely  
☐ — somewhat likely  
☐ — not at all likely

4. If genetic testing were offered to you, which of the following best describes what you would do?

Please check (✓) only one.

- ☐ I plan on having my blood taken for genetic testing and get my results immediately.
- ☐ I plan on having my blood taken for genetic testing and think about whether or not to get the results.
- ☐ I plan on having my blood taken for genetic testing in the near future (within the next six months).
- ☐ I do not plan on having my blood taken for genetic testing now, but may in the future  
(more than six months from now).
- ☐ I do not plan on having my blood taken for genetic testing now or in the future.

5. If you are found to be a gene mutation carrier for BRCA1 or BRCA2, will you?

- |                              |                             |   |
|------------------------------|-----------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have annual mammograms?  |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have clinical breast examinations every six months?                                      |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....perform <i>monthly</i> breast self-examination?  |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have a CA-125 blood test every six months?   |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have a transvaginal ultrasound every six months?   |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have prophylactic mastectomies<br>(removal of both breasts to prevent breast cancer)?    |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....have prophylactic oophorectomies<br>(removal of both ovaries to prevent ovarian cancer)? |

6. Which of the following have you done since you had genetic testing?

- |                              |                             |  |
|------------------------------|-----------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had annual mammograms?  |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had clinical breast examinations every six months?                                      |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....performed <i>monthly</i> breast self-examination?                                       |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had a CA-125 blood test every six months?   |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had a transvaginal ultrasound every six months?   |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had prophylactic mastectomies<br>(removal of both breasts to prevent breast cancer)?    |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure .....had prophylactic oophorectomies<br>(removal of both ovaries to prevent ovarian cancer)? |

Thank you very much for your participation in this research project.